

Iron overload and Hemochromatosis

Information for Patients and Their Families



You can live a healthy life,
if you get treatment early.



Department of Health and Human Services
Centers for Disease Control and Prevention

Iron overload

What is iron overload?

Iron overload is a serious chronic condition that develops when your body absorbs too much iron over many years.

Is iron overload dangerous?

If iron overload is treated before it can damage your organs, you can live a normal healthy life. However, if not treated early, it can become a serious health problem. The key is early diagnosis and treatment. For information on treatment, go to page 4.

What are the symptoms of iron overload?

Iron overload affects everyone differently. Some people feel tired. Others have heart palpitations or pain in their joints or stomach. Unfortunately, there is no definite symptom, or set of symptoms, that indicates a person has too much iron. Diagnosing iron overload can be difficult because the symptoms are like the symptoms of many other diseases.

What causes iron overload?

In the United States, iron overload is usually caused by a condition called hemochromatosis [pronounced he-mo-kro-ma-toe-sis]. Some people get iron overload because of what they eat or because of treatment for another problem, such as anemia.



Hemochromatosis (he-mo-kro-ma-toe-sis)

What is hemochromatosis?

It's a genetic condition that usually causes the body to absorb too much iron, which – after many years – leads to iron overload.

Does everyone with hemochromatosis get iron overload?

No, but many people do. However, whether they have symptoms or not, people with hemochromatosis should have their iron levels tested regularly to make sure they stay well.

It's also important for family members to get tested to see if they have iron overload. See page 8 for information on your family and hemochromatosis.

When do people with hemochromatosis begin to get sick from iron overload?

The age varies from person to person. Usually symptoms begin during middle age. Some people get sick sooner, others later.

What happens if I don't get treatment?

If iron overload is not treated, your organs can become damaged. Eventually, iron overload could cause one or more of these conditions:

- 🔴 Liver cancer
- 🔴 Heart disease
- 🔴 Impotence for men
- 🔴 Diabetes
- 🔴 Arthritis
- 🔴 Infertility and loss of periods for women
- 🔴 Cirrhosis of the liver
- 🔴 Bronze skin

Treatment for iron overload

The condition that causes iron overload cannot be cured, but it can be controlled by phlebotomy (pronounced fle-bot-o-me).

What is a phlebotomy?

It's the same procedure as when you donate blood. A nurse takes about a pint of blood from a vein in your arm. The procedure takes about an hour.

Is a phlebotomy safe?

A phlebotomy is simple, safe, and effective. However, because you'll be having frequent phlebotomies, your doctor will monitor your health more closely than if you were just donating blood.

How often must I have a phlebotomy?

Probably for about a year, you will have phlebotomies once or twice a week. How many phlebotomies you have – and how often you have them – depends on how much iron has built up in your body.

Must I have phlebotomies for the rest of my life?

Yes. However, after the iron is first lowered to a safe amount, you will have phlebotomies much less often – usually a few times a year.

Does a phlebotomy have side effects?

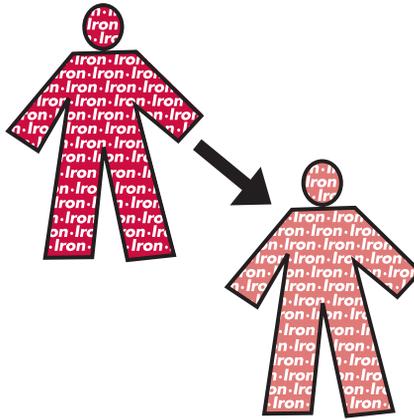
Everyone's experience is unique. Some people feel just fine. Others feel tired afterwards and like to rest for an hour or so. It's a good idea to drink water, milk, or fruit juices after a phlebotomy.

Without phlebotomies, iron overload can cause death.

Treatment is worth the effort.

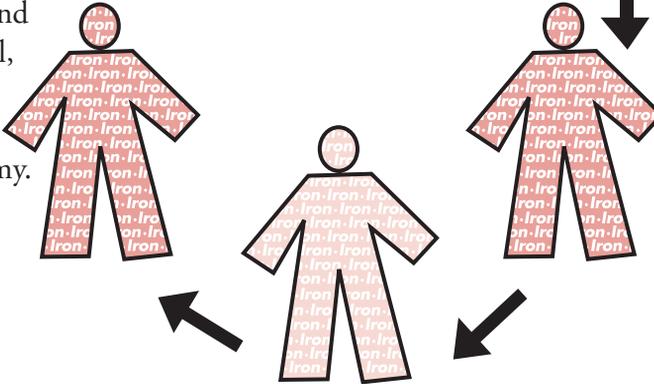
Getting your iron level back to normal

Iron in your body is too high.
You need a phlebotomy.



Each week for about a year, a nurse takes a pint or two of blood.

In time, your iron level will rise again. When it rises beyond a safe level, you need another phlebotomy.



During this time, the amount of iron in your body will decrease.

The amount of iron eventually returns to normal.

What can I do to stay healthy?

There is a lot you can do to take charge of hemochromatosis and to make sure your life is as normal and healthy as possible.



Check-ups: Have the amount of iron in your blood checked regularly.



Phlebotomy: Make sure to get phlebotomies when you need them.



Food: Don't eat raw fish or raw shellfish. Cooking destroys germs harmful to people with iron overload.



Alcohol: If you choose to drink alcohol, drink very little. Women should have less than one drink a day. Men should have less than two a day. However, if you have liver damage, do not drink any alcohol.



Iron pills: Don't take pills or supplements that have iron. Eating foods that contain iron is fine.

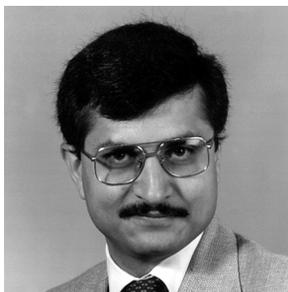


Vitamin C: Vitamin C increases the amount of iron your body absorbs. So, don't take pills with more than 500 mg of vitamin C per day. Eating foods with vitamin C is fine.



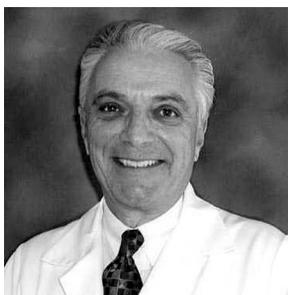
Exercise: You can exercise as much as you want. Indeed it's good to exercise so you'll stay fit.

What doctors say



"We see so many people who find out too late that they have iron overload – after lots of damage is already done. It's vital that people with hemochromatosis urge family members to get tested immediately. Then, if they have the condition, they can get treatment before there's much damage."

Prad Phatak, MD
Rochester General Hospital,
Rochester, New York



"For a year now, we've been using blood from the phlebotomies of hemochromatosis patients for transfusions. The patients are pleased to help others in this manner, and the practice has helped greatly in a time of blood shortage."

Vincent J. Felitti, MD
Southern California Kaiser Permanente,
San Diego



"CDC is interested in teaching blood banks, doctors, and patients more about early diagnosis and treatment of iron overload. An important step that patients can take toward good health is to keep getting phlebotomies."

Michele Reyes, PhD
Centers for Disease Control and Prevention
Atlanta

My family and hemochromatosis

Hemochromatosis runs in families. So, your parents, sisters, brothers, or children may also have it.

How can I help my family?

You can help by telling family members that you have hemochromatosis and that they could have it too. You can also urge them to get their iron level checked because the sooner they know whether they have iron overload, the better. People who start treatment early can stay healthy.

Why does hemochromatosis run in families?

Because hemochromatosis is caused by genes we are born with. We inherit genes from our parents, and our children inherit genes from us.

How likely are my children to have hemochromatosis?

It's impossible to answer that question because your children inherit genes not only from you, but also from their other parent. The best plan is to discuss hemochromatosis with your children's pediatrician and to have your children tested to make sure their iron levels remain normal.

Indeed, it's important for *all* close family members (your children, brothers, and sisters) to get their iron levels tested regularly. The earlier family members find out whether they have iron overload, the better their chances of leading a long, healthy life.

What patients are saying



"I am one of the lucky ones – I got treatment in time. But my brother and sister were not so lucky – both died of liver disease due to iron overload. If their disease had been diagnosed earlier, they might be alive today. Please get checked if you think there's any chance you might have the disease."

Jack C.



"I have iron overload, so I had my son tested to see if he has it too. I'm glad I did because he does have the disease, and we found out early. The doctor says if my son watches what he eats and gets phlebotomies when he needs them, he'll probably never suffer any bad effects."

Carol S.



"I have hemochromatosis, and so do my daughter, Ashleigh, and my son, Adam. We take this disease very seriously and follow our treatment regimen rigorously. Early treatment is so important to saving lives, improving the quality of life, and reducing health care costs."

Eric G.

Other information

Are people with iron overload allowed to donate blood?

There is no medical reason why blood from people with iron overload should not be used for transfusions. The Food and Drug Administration has special guidelines about handling blood donations from people with iron overload.

If you are interested in donating your blood, contact your blood bank directly to find out about its policies.

How many people have iron overload?

In the United States, about one million people have iron overload due to hemochromatosis. The condition is most common among people whose ancestors came from northern Europe.

More men than women have the condition. Perhaps women are less likely to get the condition because they lose iron when they have menstrual periods or when they give birth.



One million people in the United States have iron overload.

How to find out more

One of the best things you can do when you find out you have any type of illness is to learn as much as you can about that illness. Talk with your doctor about what to expect. Ask questions.

Sometimes it's only after you've left the doctor's office that you think of questions. After learning you have iron overload, write a list of your questions as they come to you, and then talk with your doctor again.

Remember, every question is worth asking.

For more information, check out these Internet sites:



www.cdc.gov/health/diseases.htm

Information on various diseases (including iron overload and hemochromatosis) from the Centers for Disease Control and Prevention.

www.nhgri.nih.gov/DIR/VIP

Information on genetics for physicians and nurses – National Institutes of Health.

www.gslc.genetics.utah.edu/basic/index.html

Information on genetics for patients – University of Utah*

You can get on the Internet free at all public libraries.

*Listing this Web site is solely a service to readers and does not constitute an endorsement by CDC or the federal government.

Remember

You can live a long, healthy life when you take charge of your iron overload.

- ◆ Have the amount of iron in your blood checked regularly.
- ◆ Have a phlebotomy as often as needed.
- ◆ Don't eat raw fish or raw shellfish.
- ◆ Stay away from alcohol.
- ◆ Don't take pills with iron in them.
- ◆ Don't take pills with more than 500 mg of vitamin C per day.
- ◆ Follow your doctor's recommendations.

Begin treatment as soon as possible.

- ◆ The earlier you get treatment, the better your chances of staying healthy.

Urge your family members to get tested.

